



28th ANNUAL EDUCATIONAL FORUM

APRIL 21-23, 2023

PRELIMINARY AGENDA

FRIDAY, APRIL 21:

Morning Yoga
Breakfast

WELCOME ADDRESS:

Acknowledgement of 2022 Research Roadmap and Seed Money awardees/overview of projects from Robert Kyle Award Recipients: Drs. Signy Chow and Simone Ferrero

GENERAL SESSIONS:

Current Treatment Options and New Therapies on the Horizon with Q&A, Dr. Jonas Paludo - A concise review of current treatments, the latest information about potential new treatments, and how participation in clinical trials help move novel therapies along the drug pipeline.

Newly Diagnosed with Q&A, Dr. Andrew Branagan - This simple explanation of diagnosis, symptoms, and treatment guidelines will provide newly diagnosed patients with the basics of WM and seasoned WMers with a valuable refresher course.

Experienced: Living Longer with WM with Q&A, Dr. Prashant Kapoor - Review the scientific research and clinical trials that led to improved outcomes and longer survival for WMers, as well as gain an understanding of the support dynamics and resources that are contributing to living better with Waldenstrom's macroglobulinemia (WM.)

Lunch

GENERAL SESSION:

Infection Prevention and the IVIG, COVID Balancing Act with Q&A, Dr. Andrew Branagan - Infections are the #1 cause of complications in blood cancers. Learn tips to prevent infection and explore strategies (e.g., vaccination, IVIg, etc.) to strengthen the immune system.

HOSTED FOCUS GROUPS (Pre-registration required):

I Just Want to Meet Other WM Patients - Sharon Rivet (IWMF Ed Forum Planning Committee Member)
Gathering with others who have this rare disease is an affirming experience. Join us for an informal chat with WMers you've "met" through IWMF-Connect, Facebook Support Group, LIFELINE, *Torch* magazine or Waldenstrom's Weekly

newsletter. Share your experience and learn from others who have walked in your shoes.

Young WM – Julie Richardson (IWMF Board Member)

Less than 10% of WM patients are diagnosed younger than 50 years of age. If you belong to this very rare group, join us for a discussion of relevant topics, such as how to talk to young children about cancer, sexual health, pregnancy, working during treatments, disability, life expectancy, etc.

Caregivers – Jennifer Bires, MSW, LCSW, OSW

Many family members serve as caregivers and the WM journey may be fraught with medical, emotional, and logistical challenges. Learn tips to advocate for your loved one; how to juggle caretaker tasks; self-care strategies; ways to protect your mental health; and long-distance caregiving.

Rare WM Complications - Dr. Shirley D'Sa, University of London Hospital

We're all unique! Discuss uncommon WM complications including amyloidosis, Bing-Neel syndrome, cold agglutinin disease (CAD), cryoglobulinemia, extramedullary lesions, kidney disease, lymphadenopathy (bulky disease), lytic lesions, pleural effusion, secondary cancer, and transformation to a more aggressive lymphoma.

Sound Meditation – Ann MacMullan, E-RYT 500

Relax to the sound of authentic Himalayan singing bowls, with gentle verbal guidance to further calm the nervous system. Research studies have shown that sound meditation with singing bowls reduced tension and increased feelings of spiritual well-being in its participants, and could be useful for those experiencing fatigue, chronic stress, depression, or anxiety.

Welcome Dinner and Reception – **Judith May Volunteer Award Presentation**

SATURDAY, APRIL 22:

Morning Leisure Walk or Yoga

Breakfast

WELCOME AND BEN RUDE HERITAGE SOCIETY RECOGNITION - Laurie Rude-Betts and Newton Guerin

GENERAL SESSIONS:

Great Debate in WM: BTKi or Benda-R as Standard Frontline Induction Regimen? Drs. Stephen Ansell and Jeffrey Matous - As you listen to WM specialists make a case for the best initial treatments, you will learn the drugs' pros/cons and see the decision-making process that is involved in choosing the best option for an individual patient.

Managing Complications Secondary to WM with Q&A, Dr. Sikander Ailawadhi - *One size does not fit all with WM! Learn about different WM-related secondary complications, treatment options, and management strategies. This discussion addresses Bing-Neel, Pleural effusions, and extramedullary and non-WM things like amyloidosis, cryoglobulinemia.*

Lunch

GENERAL SESSIONS:

WM Survivorship: Emotional and Psychological with Q&A, Dr. Iain Jordan - A rare disease diagnosis is often accompanied by an array of physiological and psychological challenges for both patients and caregivers. An expert, who supports people with complex illnesses, will share firsthand experiences, strategies for coping and skills to help people with rare conditions live meaningful and impactful lives.

Highlights from IWWM 11, Madrid, Spain with Q&A, Dr. Steven Treon - Listen to recommendations for understanding diagnosis and treatment guidelines based on research and content from the world's most comprehensive hematology/oncology event on Waldenstrom's macroglobulinemia (WM.)

Private one-hour Busch Stadium Tour, Leisure Walk, Yoga

Dinner on your own

SUNDAY, APRIL 23:

Breakfast

BREAKOUT SESSIONS (Pre-registration Required):

Peripheral Neuropathy: Strength/Balance– Dr. Shirley D'Sa

This session addresses the differences between WM-caused and treatment-caused peripheral neuropathy (PN). Learn about medication management and non-medication strategies, such as orthotics, balance training, acupuncture, occupational and recreational rehab, exercise, special shoes, compression socks, TENS and Scrambler therapy.

Living With WM: Before, During, After Treatment, and Quality of Life – Dr. Jorge Castillo

Life with WM will be different, but it can still be amazing! Gain insights on handling the WM journey; what to do on Watch & Wait; self-care tips during treatment; managing negative emotions; and coping with the stress of medical uncertainty.

Fatigue: Sleepy in St. Louis – Cathy Skinner

A discussion on cancer-related fatigue and its impact on quality of life, the contributing factors that can add to fatigue, and the ways in which fatigue can be managed. An overview of cancer-related fatigue (CRF) presented in a way that is meaningful to WM patients.

Nutrition: A Fresh Approach– Michelle Bratton, RD, CSO

WM specialists encourage their patients to follow a healthy and balanced diet. Learn about food challenges, healthy eating, and dietary adjustments to help optimize health during your WM journey.

Patient-Doctor Shared Decision-Making – Dr. Shayna Sarosiek

WM represents less than 1% of cancers seen by the average hematologist/oncologist. So, many patients may not be up to date with WM management. By getting involved in the decision-making process with their doctors, patients are more likely to receive better health outcomes. Learn how to be a well-informed, active self-manager of your medical care by seeking out the best consultants, questioning/verifying what they say, and monitoring/interpreting diagnostic tests and therapeutic recommendations.

Break and hotel check Out

GENERAL SESSION:

Ask the Doctors Live – Q&A Panel: Drs. Tom Hoffmann, Steven Treon, Jorge Castillo, Shayna Sarosiek and Jeffrey Matous - A panel of leading WM specialists answer, and sometimes debate, questions about WM from the Ed Forum audience.

CLOSING REMARKS: Dr. Newton Guerin, IWMF President & CEO